



RON CHAPMAN, MD, MPH
Director & State Health Officer

Vital Statistics Advisory Committee (VSAC)
Vital Records Protection Advisory Committee (VRPAC)
Joint Meeting
Meeting Minutes for Wednesday, January 9, 2013
9:00 AM



EDMUND G. BROWN JR.
Governor

ATTENDEES:

Convener: Krista Christian, MBA, Chief, Vital Statistics Unit

Committee Members:

Present: Jonathan Teague, MCRP, Malaika Singleton Duran, PhD, Emily Putnam-Hornstein, PhD, Veronica Wogec (on behalf of Tony Agurto)

Phone: David Grant, PhD

California Department of Public Health (CDPH) Staff:

Present: Laura Lund, Science Advisor, Julie Turner, Cindy Tanaka-Fong, Emily Stotlar

CALL TO ORDER: The meeting was called to order at 9:05 AM

A/B. WELCOME/INTRODUCTIONS: Krista announced that this was a public meeting conforming to the Bagley-Keene open meeting act. Members of the public are allowed to attend and welcome to participate at the end of the meeting.

Krista informed everyone that the meeting was being recorded to assist with minute taking. Krista introduced CDPH staff. Krista welcomed Emily Stotlar who previously worked in the Data Quality Management Unit on special projects but is transitioning into the Vital Statistics Unit.

No members of the public attended the meeting.

Research protocols are available for review on our Department's SharePoint site. Protocols are uploaded up to 3 weeks prior to the VSAC meeting and members are encouraged to download and review them early to avoid issues.

We received an announcement from Sue Holtby that she is withdrawing from the committee as she completed her 3 year term. We would like to thank her for her service. We currently have 7 members on the committee. We are still looking for new recruits. David Grant commented that he joined the committee the same time as Sue Holtby. He asked about the expected years of service. Krista responded that it is 1-2 years for the VRPAC and 3 years for

VSAC. There is nothing in statute that says committee members cannot serve longer than the specified time.

C. APPROVAL OF MINUTES FROM THE PREVIOUS MEETING:

Jonathan Teague motioned to approve the November 14, 2012 meeting minutes. Emily Putnam-Hornstein seconded the motion. All Committee members voted to approve the minutes. There were no oppositions. There was one abstention.

D. VSAC RECOMMENDATIONS FROM THE PREVIOUS MEETING:

Attachment 1, the State Registrar's Response to VSAC Recommendations, is a recap of recommendations from the last meeting.

E. NEW BUSINESS:

Ten projects were reviewed.

The first project reviewed by the Committee was:

Project Title: "Maternal and Infant Health Assessment (MIHA)"

Principal Investigator(s): Paula Braveman, MD, MPH, Professor of Family and Community Medicine, University of California, San Francisco, School of Medicine

Project Type: Continuing Project

CPHS Approval: Approved

Project No.: 12-10-0819

Expiration: December 6, 2013

File(s) Requested: 2013 Custom birth dataset

Requested Identifiers: Select variables

Personal Contact: Yes

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: No discussion.

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Emily Putnam-Hornstein motioned to recommend approval of the data request. Jonathan Teague seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval. There were no oppositions. There was one abstention. Motion carried.

The second project reviewed by the Committee was:

Project Title: "Investigation of the Relation of Fine Particulate Air Pollution and Temperature to Mortality in California"

Principal Investigator(s): Rachel Broadwin, MPH, Research Scientist, Office of Environmental Health Hazard Assessment (OEHHA), California Environmental Protection Agency (CalEPA)

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-05-0246

Expiration August 2, 2013

File(s) Requested: 2008-2011 Death Statistical Master File (selected variables)

Requested Identifiers No Personal Identifiers

Personal Contact: No

Identifiers Released: No

History: New Research Project

VSAC Discussion: No discussion.

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Jonathan Teague motioned to recommend approval of the data request. Emily Putnam-Hornstein seconded the motion.

VSAC Vote: Committee members voted in favor of recommending approval of the data request. There were no oppositions. There was one abstention. Motion carried.

The third project reviewed by the Committee was:

Project Title: "The Program Monitoring and Evaluation of California's Family Planning Program: Family PACT"

Principal Investigator(s): Marina Chabot, Office of Family Planning, Department of Health Care Services

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-06-0310

Expiration: August 2, 2013

File(s) Requested: 2011 Birth Statistical Master File (entire file)

Requested Identifiers: Name, Certificate Number, Address

Personal Contact: No

Identifiers Released: No

History: New Research Project

VSAC Discussion: Concerns brought up by the committee included the release of marital status and SSN, the identity of the principal investigator, and if a HIPAA waiver was needed. Clarification was made that the Principal Investigator (PI) is aware we would not release marital status or SSN. The PI was identified as her signature was on the access agreement. Vital statistics are exempt from a HIPAA waiver but they would need a HIPAA waiver as Medi-Cal is one of the providers. Julie confirmed that the project was approved by CPHS.

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Jonathan Teague motioned to recommend approval of the data request. Emily Putnam-Hornstein seconded the motion.

VSAC Vote: The Committee members all voted in favor of recommending approval of the data request. There were no oppositions. There was one abstention. Motion carried.

The fourth project reviewed by the Committee was:

Project Title: "National Children's Study"

Principal Investigator(s): Christina Chambers, PhD, MPH,
Department of Pediatrics, Family and Preventive Medicine, Skaggs
School of Pharmacy and Pharmaceutical Sciences (SSPPS), University
of California San Diego

Project Type: Continuing Project

CPHS Approval: Approved

Project No: 08-02-58

Expiration: February 1, 2013

File(s) Requested: 2011 Custom birth dataset (select variables)

Requested Identifiers: No Personal Identifiers

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: The committee wanted to know if the project had CPHS approval. Krista stated if it is pending, we would not release the data until we receive CPHS approval. Clarification was made that if the project was approved through February 1, we would let them know they can only use the data until February 1 unless there is a subsequent renewal.

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Emily Putnam-Hornstein motioned to recommend approval of the data request. Jonathan Teague seconded the motion.

VSAC Vote: The Committee members voted in favor of recommending approval of the data request. There were no oppositions. There was one abstention. Motion carried.

The fifth project reviewed by the Committee was:

Project Title: "Out-of-Hospital Sudden Cardiac Death Records Review"

Principal Investigator(s): Benjamin Colburn, Electrophysiology
Services, University of California San Francisco

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-06-0459

Expiration: October 4, 2013

File(s) Requested: Custom death dataset 2007-2013 (select variables)

Requested Identifiers: California identifiers

Personal Contact: Yes

Identifiers Released: No

History: New Research Project.

VSAC Discussion: David Grant commented that the proposal was brief and did not have much detail as it was not certain what they were proposing to do. His understanding was that they were asking to do two things:

- Obtain consent from us to contact the next of kin to obtain a tissue sample. This would involve the use of PID for contact information.
- Ensure the sampling of San Francisco is representative of deaths in SF by cardiac arrest

There is no information as how they would be contacting the next of kin.

Other committee members also expressed concern with the protocol.

VSAC Recommendation(s): Approve the data request. For clarification purposes, and since human subject contact is involved, a suggestion was made that CPHS approval be in place first before the data is released.

VSAC Motions: Jonathan Teague motioned to review the protocol after CPHS approval is received. Emily Putnam-Hornstein seconded the motion.

VSAC Vote: Committee members all voted in favor of reviewing the data request at the next VSAC meeting, once CPHS approval is received. There were no oppositions. There was one abstention. Motion carried.

The sixth project reviewed by the Committee was:

Project Title: "Predictors of Long-term Outcomes in California Children with Central Nervous System (CNS) Tuberculosis (TB)"

Principal Investigator(s): Alexandra Duque-Silva, MD, California Department of Public Health, Tuberculosis Branch

Project Type: New Project

CPHS Approval: Requested

Project No.: Pending CPHS approval

Expiration: Pending CPHS approval

File(s) Requested: 2001-2011 Death Statistical Master File (select variables)

Requested Identifiers: Decedent's name

Personal Contact: No

Identifiers Released: No

History: New Research Project.

VSAC Discussion: Comments included concern for the small sample size. A suggestion was made that we could be flagged with the researcher's attention.

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Jonathan Teague motioned to recommend the approval of the data request. David Grant seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. There was one abstention. Motion carried.

The seventh project reviewed by the Committee was:

Project Title: "Mortality and Support on Online Social Media"

Principal Investigator(s): James H. Fowler, PhD, University of California, San Diego

Project Type: New Project

CPHS Approval: Requested

Project No.: Pending CPHS approval

Expiration: Pending CPHS approval

File(s) Requested: 2000-2010 Death Statistical Master File (select variables) Dr. Fowler will be using the same data set previously obtained for two of his projects.

Requested Identifiers: California identifiers only

Personal Contact: No

Identifiers Released: No

History: New Research Project.

VSAC Discussion: The Committee expressed concern for how data would be linked to Facebook information based on the use of the name. A question was raised about the privacy agreements on Facebook accounts? People are looking at Facebook as a "treasure trove" of information of different kinds. There is currently no general consensus of how information is accessed on Facebook, what is permissible and what is not, and how this can be monitored. It was suggested that the request be reviewed/approved by CPHS and subsequently reviewed at the next VSAC meeting. Possibly CDPH staff could discuss with the CPHS reviewers. The committee strongly advised that review by CPHS be approached with caution due to the novel nature of the request. Concern was also expressed at the requester's response to the question of whether they would be using an outside contractor, as reference was made to use of the Facebook server. Jonathan suggested that this request be remanded pending CPHS approval.

VSAC Recommendation(s): The committee recommended that CDPH staff contact CPHS and discuss with appropriate staff who is responsible for this protocol.

VSAC Motions: Jonathan Teague motioned to review the protocol at the next meeting, after we receive CPHS approval. Emily Putnam-Hornstein seconded the motion.

VSAC Vote: Committee members all voted in favor of reviewing the protocol at the next meeting, after we receive CPHS approval. There were no oppositions. There was one abstention. Motion carried.

The eighth project reviewed by the Committee was:

Project Title: "A Binational Population-based Study of Birth Outcomes of Mexican-Origin Women Living in California and Mexico"

Principal Investigator(s): Sylvia Guendelman, PhD, University of

Berkeley

Project Type: Continuing Project

CPHS Approval: Approved

Project No.: 12-08-0681

Expiration: October 4, 2013

File(s) Requested: 2008, 2009 Birth Statistical Master File (select variables)

Requested Identifiers: No Personal Identifiers

Personal Contact: No

Identifiers Released: No

History: Previous Data Request.

VSAC Discussion: No discussion

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Emily Putnam-Hornstein motioned to recommend approval of the data request. Jonathan Teague seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. There was one abstention. Motion carried.

The ninth project reviewed by the Committee was:

Project Title: "Linkage of Medi-Cal Administrative Data with Data from the California Birth Statistical Master File"

Principal Investigator(s): Aldona Herrndorf, MPH, Department of Health Care Services

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-07-0571

Expiration: Determination of No Research

File(s) Requested: 2010 & 2011 Birth Statistical Master File (select variables)

Requested Identifiers: Name, Certificate Number, Address

Personal Contact: No

Identifiers Released: No

History: New Research Project.

VSAC Discussion: Committee expressed concern with data retention and wanted clarification on destruction of the data on the SAS server once the project is completed.

VSAC Recommendation(s): Approve the data request with stipulation that the PI indicates how the data will be returned or destroyed pending the project termination, pertaining to the data on the server.

VSAC Motions: Emily Putnam-Hornstein motioned to recommend approval of the data request. Jonathan Teague seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

The tenth project reviewed by the Committee was:

Project Title: "Environmental Health Tracking and Childhood Cancers in California"

Principal Investigator(s): Julia Heck, PhD, Researcher, University of California, Los Angeles

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-05-0270

Expiration: August 2, 2013

File(s) Requested: 2010 and 2011 Birth Statistical Master File (select variables), 2010 and 2011 Death Statistical Master File (select variables)

Requested Identifiers: BSMF (Name, Certificate Number, Address), DSMF (Name, Certificate Number, Address)

Personal Contact: No

Identifiers Released: No

History: New Research Project.

VSAC Discussion: No discussion.

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Jonathan Teague motioned to recommend approval of the data request. Emily Putnam-Hornstein seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

F. ITEMS FOR DISCUSSION: Krista asked the Committee to refer to Item F, Recap of Data Requests approved in the Vital Statistics Unit, Attachment 3. Twenty-five data requests that did not require VSAC/VRPAC review were reviewed and approved by the Health Information and Research Section.

G. PUBLIC COMMENT: There were no members of the public attending the meeting.

H. AGENDA ITEMS: Krista asked the Committee if there were any agenda items for the next meeting. There were no agenda items.

I. ADDITIONAL DISCUSSION: Malaika Singleton Duran told the Committee she is representing the Legislature, in the capacity of consultant, and that she would not be voting or making any motions.

J. MEETING ADJOURNMENT: Emily Putnam-Hornstein motioned to adjourn the meeting. Jonathan Teague seconded the motion. Committee members all voted in favor of adjourning the meeting at 10:05 A.M.